

Shristy Poudel

**Counseling in HIV/AIDS Patients**

Stigma and barriers of counseling

A Literature review

Thesis

Spring 2016

Faculty of Health Science and Social Work

Degree programme in Nursing



SEINÄJOKI UNIVERSITY OF APPLIED SCIENCES

## **Thesis Abstract**

Faculty: School of Health science and Social work

Degree programme: Bachelor's Degree in Nursing

Specialisation: Registered Nurse

Author/s: Shristy Poudel

Title of thesis: Counseling in HIV/AIDS Patients

Supervisor/s: Mari Salminen-Tuomala PHD, Senior Lecturer & Johanna Heino MNSC, Senior Lecturer.

Year: 2016

Pages: 36

Numbers of appendices: 1

---

HIV/AIDS has developed into a very serious disease over the last decades. The disease has proven to be fatal and has no treatment found yet but with proper counseling and good care a patient can stay healthy for a long time.

The aim of the thesis is to describe the counseling for HIV/AIDS patients in the region most affected like Africa and produce new information on this particular area.

The method used in writing this thesis is literature review and the content in it were collected using Pub med , CINAHL , Medic and Nelli databases including the scientific journals that has been published so far.

The research question used was: what kinds of stigma are there attached with HIV/AIDS? What kind of changes can counseling bring in general public's attitude in the places affected mostly by this disease? And how much does counseling help in prevention of the disease?

Articles were searched by the use of title, abstract and then the analysis was done by inductive content analysis.

**RESULT:** At the end of the thesis it was found that prevention of HIV/AIDS is possible by providing knowledge and information to the people so they could reduce risk behaviors. It was found that people diagnosed with HIV did not get themselves in for a proper care plan in an early stage and had fear of lots of stigma from the community they are living in . it was also found that there was not a significant amount of change in the disease incidence even when counseling was done. Counseling done just was not enough and that community based interventions work the best in controlling and preventing the disease in lots of countries affected.

**KEYWORDS:** HIV/AIDS, Prevention, Counseling, Barrier, Stigma



## TABLE OF CONTENTS

Shristy Poudel .....	1
Stigma and barriers of counseling .....	1
A Literature review .....	1
SEINÄJOKI UNIVERSITY OF APPLIED SCIENCES .....	2
Thesis Abstract.....	2
Faculty: School of Health science and Social work .....	2
TABLE OF CONTENTS .....	4
Tables and figures .....	6
Abbreviations.....	7
1 INTRODUCTION.....	8
2 HIV AND AIDS AS DISEASE.....	10
2.1 HIV/AIDS .....	10
2.2 Transmission .....	12
2.3 Symptoms of HIV.....	12
2.4 Diagnosis of Acute HIV Infection .....	13
2.5 Patient Counselling.....	14
3 Aim and Objective of the thesis.....	17
4 Data collection and analysis.....	18
4.1 Systematic Review .....	18
4.2 Obtaining the content .....	19
<b>Figure 1 : Search results done for the articles.</b> .....	19
4.3 Content Analysis.....	20
<b>Figure 2 .1: Example of inductive content analysis process</b> .....	21
5 Results .....	25
5.1 Testing and Counselling .....	25
5.2 Stigma of HIV/AIDS .....	26
<b>Figure 3 : Demographic characteristic survey of HIV/AIDS inn</b> <b>survey</b> .....	27

5.3 Experience and fears of the patient diagnosed with HIV/AIDS .....	28
5.4 Barriers of HIV/AIDS counselling.....	30
5.5 Community based interventions and voluntary counseling .....	31
6 Discussion.....	33
6.1 Ethics and Reliability .....	33
6.2 Analysing the results .....	34
6.3 Further studies.....	35
6.4 Use of the thesis paper.....	35
BIBLIOGRAPHY .....	37
<b>APPENDIX 1. Process of searching for information .....</b>	<b>1</b>

## Tables and figures

1 . Search results done for the articles.....	18
2. Example of content analysis .....	20
3. Demographic characteristic survey of HIV/AIDS in survey.....	25

## **Abbreviations**

<b>HIV</b>	Human Immunodeficiency Virus
<b>AIDS</b>	Acquired Immunodeficiency Syndrome
<b>CART</b>	Combination Anti Retroviral Therapy
<b>MTCT</b>	Mother to child transmission
<b>STI</b>	Sexually Transmitted Infection
<b>CTR</b>	Counseling Testing and Referrals
<b>HCT</b>	HIV Counseling and Testing
<b>ART</b>	Anti Retroviral Treatment

## 1 INTRODUCTION

The HIV/AIDS came into discovery around the year 1981 in United States of America in some of the young homosexuals and drug users. (Kartikeyan, Bharmal, Tiwari, & Bisen 2007, 3).

Although in the earlier days of its discovered among the young homosexuals and drug addict but in later research it was found that other youth as well were starting to show the same signs and symptoms, and was discovered that the disease was being transmitted by sexual intercourse and also by sharing of the same needles. It was also found that the disease was also transferred from mother to the fetus. (Nye, Parkin 1994, 1).

HIV (Human Immuno Virus), a retro virus is closely linked to AIDS, the advanced stage of HIV leads to develop into ASIDS. Retro virus is an RNA virus with two copies of an 8500 base pair plus-stranded RNA genome that is capable of inserting and efficiently expressing its own genetic in the host cell's genome, by transcribing its own RNA into DNA that is integrated into host genome. (SEGON 1992, 621)

AIDS Acquired immunodeficiency syndrome is a condition intimately linked to the retro virus, HIV (Human immunodeficiency syndrome); although long-term survival of the HIV infected subject is possible, once clinical AIDS develops it responses only temporarily to therapy. 5 million are infected in AFRICA (WHO Estimates 1991) and 10 million are positive worldwide. (SEGON 1992, 13).

AIDS can be described as an illness, which can lead in developing one or more kind of major disease in the person infected.

Even though the disease was first seen in North America and Europe, HIV/AIDS has now been seen though out the world and major focus of this epidemic disease is to develop resources to fight against it especially in the poor countries. (Adler, 2001, 2 )



The aim of the study carried out is to find information on the stigmas attached with the disease and the barriers regarding the counseling and prevention of the disease from spreading further.

The objective of the thesis is to collect as much information helpful to prevent the disease by using scientific articles available and analyzing the information to help understand the stigmas, fears of the patient and the barriers while counseling them.

During the process of the research it was found that a lot of people won't get the proper knowledge and information on the prevention of the diseases and also the care that is needed for the quality of the life of those who have been infected. If given proper information on the disease it can reduce the risk behavior. Counseling given just to the infected person was not enough, counseling in a community level was needed to prevent further spreading of the disease.

## 2 HIV AND AIDS AS DISEASE

### 2.1 HIV/AIDS

Human immunodeficiency virus is a virus belonging to the retro virus, which attacks the cells of human being by impairing and destroying the cells. When the disease progresses the immune system of the body becomes weaker and so the person has more capacity of catching the infection easier.

Acquired immunodeficiency syndrome is the advance level of the infection due to HIV. It could take about 10-15 years for HIV positive person to develop into AIDS.

HIV is transmitted to people through unsafe sex, transfusion of contaminated blood, through the use of contaminated needle and also from HIV positive mother to the infant during pregnancy and/or childbirth and breastfeeding (According to World Health Organization, 2012)

The key point of the HIV infection is infection and viral replication with T-lymphocyte, which has CD4 antigen. Once a person has HIV infection they also can develop disruptive blood monocytes and B-lymphocytes.

HIV infection can further be divided into stages such as:

Viral transmission: HIV infection gets transmitted basically by sexual intercourse both anal and vaginal, with contaminated blood like needle or blood transfusion or mother to fetus transmission.

Acute/primary HIV infection: The period of 1-4 weeks after the virus has been transmitted acute HIV infection develops where an increased level of HIV RNA is found with the absence of HIV antibody.

Seroconversion: Stage where HIV positive antibody progresses in about 4 weeks of the acute infection.

Asymptomatic HIV infection: This stage of the infection may last for many years, in average 8-10 years. During this stage the CD4 count will decrease slowly and somewhat same level of HIV RNA.

Early symptoms of HIV infection: Some symptoms like vaginal candidiasis, herpes zoster, peripheral neuropathy, diarrhea, mild weight loss can be seen.

AIDS: The stage where the number of CD4 cells are  $<200/\text{mm}^3$ , CD4 cell percentage of the total lymphocytes is  $<14\%$ , or any of the many AIDS related opportunistic infections like pneumonia, cryptococcal meningitis, Candida esophagitis, CNS toxoplasmosis, tuberculosis, and non-Hodgkin's lymphoma occurs.

Advanced HIV disease : The CD4 cell count is less than  $50/\text{mm}^3$ . Usually the person suffering might die at this stage. Common late stage opportunistic infection such as retinitis, colitis occurs. (Sax, Cohen, Kuritzkes, 2008 6-8)

## 2.2 Transmission

Kartikeyan, Bharmal & Tiwari (2007) write that there are multiple ways of transmission of the HIV from infected person to the healthy one and some of them are: Sexual intercourse, receptive sex, presence of genital lesions and other sexually transmitted infections. Usage of the same needle used by the infected person, in many cases drug abusers get infected this way. Other major factor being blood transfusion and mother to fetus transmission.

According to Kartikeyan et al 2007 social factors such as no sex education and proper knowledge about sex leads to transmission of the disease especially in the underdeveloped and poor countries like INDIA. Some myths in some part of the world regarding the disease also lead in uncontrollable amount of new cases. Basically, Lack of proper education to the people about the disease and how it is transmitted is also a reason for more and rapid rise of the numbers of new cases of HIV.

The potency of the HIV virus to transmit sexually is between 70-80%. The risk of getting HIV infected or transmission through the blood and blood product is 3-5%, needle or syringes are 5-10% about 5-10% in case of perinatal Transmission by needle stick injuries to health workers is less than 0.1%. HIV transmission is a huge way of transmission but it is not as difficult to prevent. ( Adler, 2001 2 )

## 2.3 Symptoms of HIV

Signs and symptoms of HIV positive patient may present could be fever, Pharyngitis, Arthralgia or myalgia. Some neurological symptoms like headache are very common. Also neuropathy can occur in some patient. Some other symptoms like oral or genital ulceration, thrush, nausea, diarrhea, vomiting and weight loss could be present. Besides the symptoms that a person positive with HIV, there could be signs that could be found out by the use of lab test.

Some of the lab test that could help determining that a person might have HIV infection is: CBC lymphopenia, which is followed by lymphocytosis, this kind of finding is very common. Increased level of the transaminases in some common patient. In some rare cases the CD4 cell count could be decreases but this happens in a very small amount of infected people. (Sax, Cohen 2013 14-17).

The symptoms of the HIV/AIDS after establishing that a person has been diagnosed as HIV positive can also be categorised as the stages of the HIV infection. During the first stage of the HIV infection a person might be asymptomatic where as in a particular stages after the infection has progressed a person might suffer recurrently by a set of diseases like Candidiasis of the Bronchi, trachea or lungs, candidiasis of the esophagus, cervical carcinoma, herpes simplex, histoplasmosis, disseminated or extrapulmonary, lymphoma, progressive multifocal leukoencephalopathy, cervical dysplasia, bacillary angiomatosis. (Nye & Parkin 2005 39-41)

As disease develops itself from an earlier stage to advanced stages, CD4 numbers will fall and the individual suffering will start getting minor illnesses at first which are not life threatening but these signs do mean that the HIV infection is progressing and so there might development of AIDS. When this happens it might bring in major opportunists infections, which might cause mortality. (Nye et al 2005 42)

## **2.4 Diagnosis of Acute HIV Infection**

Some of the ways of the diagnosis of HIV infection as written in the book HIV essentials by Paul E. Sax, Calvin J. Cohen are:

To retrieve the HIV antibody so that prior disease could be excluded.

To order a viral load test (HIV RNA PCR), HIV RNA will help confirm that there is HIV infection before the seroconversion when the HIV antibody is simultaneously negative.

If any of the tests are positive, it is very important to carry out the HIV RNA and HIV antibody test again.

Other tests such as serologies or test if HIV RNA test comes out negative can also be carried out. In such cases test of viral or bacterial respiratory pathogens could be cultured. Also Hepatitis serologies as needed can be obtained and carried out for the further diagnosis and clear results.

## **2.5 Patient Counselling**

According to British Association For Counseling (BAC) 1986, counseling can be defined as skilled and principled usage of the relationship to promote self-knowledge and obtaining ones' emotions with the maximum growth of personal assets. The main aim of the counseling is to provide one with the opportunity to live more satisfyingly and resourcefully. The issues that need counseling might be different but it might be concerned with developmental concerns, discussion of a problem and finding a solution, taking a decision, coping in time of crisis , developing knowledge and working in the feeling of inner conflict and growth of a personal relationship.

Anssi peräkylä (2005) HIV counseling is a conversation between the patient and the counselor with an aim of prevention of the transmission of HIV and to provide psychological support needed by the patient and to those who are affected indirectly. Counseling a person with HIV seeks two main aims, first to prevent the virus from further spreading to the healthy individuals through addressing both infected and non-infected people and on the other hand it seeks to provide psychological help that both the infected party and or his/her family, friends might need which in turn will help in developing confidence in patient and the family in coping with the disease and help improving the relationship.

Like in any other counseling, even in HIV counseling there are three aspects to the method, which are delivering the information, explanation of the information and guidance according to the necessity.

The HIV counseling unlike other counseling requires the counselor to hold a strong knowledge, background and awareness of the disease and ways of counseling. There are several things to keep in mind while counseling HIV patient, like circular questioning for example what are your main concerns now? Or what are your family's concern now? Etc. Future oriented hypothetical questions can also help in counseling. Counselor can use 'What', 'Why', 'How' question might help the counselor in building an understanding of the stage of the patients' mental status and help them gather as much information to assist them to help the patient and deliver the appropriate counseling needed at the situation. (Anssi peräkylä 2003).

Having a proper counseling technique in any type of medical and psychological counseling is of most importance. Some of the counseling techniques are Eclectic technique for group therapy, classic gestalt technique, non-verbal and metaphorical technique, Art therapy, cognitive behavioral therapy, rational emotive behavior therapy or reality therapy, classic behavioral technique. Using any of these therapies counselors can help overcome the issues of a patient. (Rosemary A. Thompson 2003).

The quality of the counseling is parallel to the content, implementation and benefit of the patient counseling and counseling material and procedure. A proper counseling is very well planned and patient-orientated. It thinks about the history of the patient and keeps in mind on the knowledge that the patient about the disease. (Kaakinen, Kääriäinen & Kyngäs, 2012)

There should be a clear line of communication process between health professionals and the patient, which will help establish and develop a relationship between them. Good communicative relationship will help provide the exchange of the information that is essential to get to know the patients' health condition and the situation they are in. It also helps to analyze how the treatment is working on the patient's lifestyle. The health care professional counseling a patient should have few qualities like the understanding of the illnesses of the patient. Taking

every patient's experience as a unique one. Counselor should be in an impartial relationship with the patient. It helps a great deal if the professional can build a therapeutic alliance with the patient to meet mutually understood goals of the therapy. Also there should be a level of self-awareness of a personal thinking or opinion that might have an effect on the patient. Also the health care professional involved in the counseling should encourage the patient to share experiences because they might have unanswered questions and many misunderstandings. They may have experienced problems with the treatment or therapies that they are in. This could also help them make a decision regarding their treatment. (E.Tsang, 2008)

In conclusion, there are some key ideas that are the core elements of an effective counseling. Some of which are: Background- asking an open ended question which helps counselor to know about the culture, lifestyle of the patient, possessing a genuine interest in helping, taking into account of organizational realities, responding to empathic opportunities, taking consent of the counseling , making enough space for the patient, finding a focus and flexible use of counseling methods.(Macleod & Macleod, 2007)



### **3 Aim and Objective of the thesis**

The topic of the bachelor thesis is Counseling HIV/AIDS patient, Stigma and barriers of counseling. The main objective of the thesis is to collect more information on the stigmas and the barriers that stand in a way to prevent new cases of the disease. Counseling done for the patient who has been diagnosed with HIV infection. The aim of the thesis is to develop clear understanding and collect information on the counseling done for the HIV patient from nurses and the changes that counseling brings in the life of the patient and also those who are affected indirectly. The aim is also to develop an understanding on barriers and difficulty during counseling faced by the nurses. There are few research questions that has helped finding the information.

The research question for the bachelor thesis is:

1. What kind of stigmas are affecting the patient with HIV infection?
2. What kind of changes can counseling bring in general public's attitude in the places affected mostly by this disease in quality of life and prevention of further spreading of the disease?
3. How much does counseling help (voluntary) in giving more knowledge about the disease in overall public?

The information for the thesis will be searched keeping these research questions in mind.

## 4 Data collection and analysis

### 4.1 Systematic Review

It was already decided that the form of our thesis would be done in Systematic literature review hence; I used systematic literature review for this thesis.

Systematic reviews attempt to bring same level of rigor to reviewing research evidences should be used in producing that same research evidence in the first place. Systematic reviews should be based on a peer-review protocol so that they can be replicated if necessary. High quality systematic reviews seek to:

1. Identify all published and unpublished evidence.
2. Select studies or report for inclusion.
3. Assess the quality of each study or report.
4. Synthesize the finding from individual studies or report in an unbiased way.
5. Interpret the findings and present a balanced and impartial summary of the findings with due consideration of the flaws in the evidence. (Hemingway, Brereton , 2009.)

The process of carrying out the systematic reviews has been very well described in the health sectors or social and education sector. There is an increasingly high profile of evidence-based guidelines in the education and social sciences field. The key element of the development is a brand new focal point on the rational and on point procedure of the systematic reviews. The fact that systematic reviews aims to limit probable selection, reporting can educate protocols, practices and research. (C. Torgesson, 2003)

Systematic review can give a very reliable and prognostic conclusions of complete research. The review done in systematic review is a research process initiated to give a very deep results to clinical questions and to carry a

best practice. Systematic reviews can be both quantitative or qualitative in features or used mixed process for more complete review. (Holly et al. 2012)

## 4.2 Obtaining the content

Obtaining the content for the thesis was started as soon as the topic was chosen. Inclusive and exclusive criteria was chosen to make it easier to obtain the data. The information and the data were obtained using different databases from the Internet. The information was obtained through searching for the appropriate scientific articles and journals that were available in different databases. The inclusive criteria that were used were articles published from 2000-2013 and the articles were all in English language. The words that was used to research the article were counseling HIV/AIDS patient and counseling and HIV/AIDS.

During the search filtration of full text and full free text was used to make it easier. EBSCO host (Cinahl) database search and PUBMED search were used to search for the articles, during the search about 924 articles were found from EBSCO and 1210 from PUBMED and then the abstract and the result of 38 articles were read and at the end selected 8 from EBSCO host and 5 from PUBMED for the thesis, in total 13 articles that were the most close to the thesis topic.

**Figure 1 : Search results done for the articles.**

DATABASE	KEYWORDS	HITS	USED
Chinahl	HIV/AIDS and counseling  Barriers of counseling in HIV/AIDS	924	8

Pubmed	Counseling HIV/AIDS patient  Counseling in HIV/AIDS.	1210	5
--------	--	------	---

### 4.3 Content Analysis

According to Kimberly A. Neuendorf (2002 ,1) content analysis can be defined as systematic, objective, quantitative analysis of message characteristics in quantitative research.

Content analysis has been defined as a systematic replicable technique for compressing many words of text into fewer content, categories based on explicit rules. Content analysis enables researchers to shift through large volume of data with relative ease in systematic fashion. It also allows inferences to be made which can then be collaborated using other method of data collection. ( Stemler, 2001).

Basics of the Qualitative content analysis can be described as:

Inserting the material within the communicative context- the advantages of the content-analysis is that it is a system of strong communicative science, methodic order required practice, division in the focal point of resolution and the information is always observed as a loop to a clear-cut point of delivery.

Systematic, rule bound procedure- Constitution of a firm procedure proto-type is the most important thing. All the accurate tracks and agreement should be made under systematic and tested rules.

Categories in focus of analysis- Categories are the key point in content analysis. The system of categorizing builds the central concept of analysis process.

Object reference in place of formal techniques- The process of qualitative content analysis can't be all placed on techniques, which can be used anywhere or

everywhere, the affiliation with the specific article is very important. (Mayring 2014).

**Figure 2 .1: Example of inductive content analysis process**

ORIGINAL TEXT	SIMPLIFICATION	SUB-HEADING
<p>“Effective HIV prevention measures should ideally emphasize human dignity, responsibility, voluntary participation, and empowerment, through access to information, service and support system. A thorough understanding of common values and belief systems also helps to identify positive values and practices that can facilitate and more effectively promote HIV interventions.” (Salam A Rehana., Bhutta A Zulfiqar, 2012)</p> <p>“Several interventions have led to reduced HIV incidence in clinical trials, including early treatment of HIV infection, use of</p>	<p>HIV can be prevented largely by voluntary participation of the infected people and the accessibility of the services to these people and when they have proper information about the disease and have strong support.</p> <p>Interventions done have resulted in decreased HIV infections by encouraging antiretroviral therapy.</p>	<p>Community based interventions and voluntary counseling.</p>

<p>antiretroviral therapy to prevent mother-to-child transmission, chemoprophylaxis, and male circumcision". (Thomas J Coates et al, 2014)</p>		
<p>"More often than individual-level barriers, respondents described system-level barriers. This included barriers relevant to HIV care system, criminal justice system, or health insurance system. Lack of financial means or health insurance was most often listed as the primary reason they hadn't accessed any HIV-related follow-up services including case management". (Pamela M Garland, et al 2011)</p> <p>"Effective strategies to increase knowledge and reduce risk behavior are urgently needed. Voluntary counseling and testing (VCT) provides</p>	<p>Not having enough financial support was seen as a basic barrier for patient not taking part in HIV care and follow up care.</p> <p>Besides the need of plans and programs to reduce the risk behavior and increase the information to the people, still the</p>	<p>Barriers of HIV counseling.</p>

<p>the opportunity to educate and promote behavior change. However the uptake of testing services remains low and research in developed and developing countries has highlighted a number of barrier accessing VCT including HIV/AIDS-associated stigma". (Samaya Mall et al)</p>	<p>number of testing is low and research in all the countries has shown numbers of barriers amongst which is stigmas related to the HIV/AIDS.</p>	
<p>"Confirming that they were HIV-infected left them depressed and fearful of how others would treat them. This caused many to isolate from the public even before they developed symptoms. Self-inflicted stigma was common in the early days of confirming they were HIV-positive ". (Barbara Nyanzi-Wakholi, et al)</p>	<p>After being HIV-positive patient were fearful of how others would treat them which caused them to withdraw from socializing even before any symptoms were seen</p>	<p>Stigma of HIV/AIDS</p>

**Figure 2.2 : Example of Inductive content analysis process**

Preparation phase Data searching	Organization phase Data Analysis	Theory Result
<ul style="list-style-type: none"> <li>• HIV/AIDS disease</li> <li>• Patient counseling</li> <li>• Barriers</li> </ul>	<ul style="list-style-type: none"> <li>• HIV/AIDS as a disease, symptoms, diagnosis, treatment</li> <li>• Voluntary counseling and antiretroviral therapy</li> <li>• Types of barriers on counseling for patient and health professionals</li> <li>• Stigmas of HIV/AIDS and fear of the patients</li> <li>• Testing of HIV/AIDS; availability of the services</li> </ul>	<ul style="list-style-type: none"> <li>• Testing and counseling crucial for prevention and care</li> <li>• Self-inflicted, family-inflicted, community-inflicted stigmas are biggest barriers</li> <li>• Fear of being isolated from the society, family, and impending death</li> <li>• Voluntary counseling and community based interventions are more reliable and effective.</li> <li>• Lack of health services and finance also major problem.</li> </ul>



## 5 Results

### 5.1 Testing and Counselling

Many people who are already infected with HIV do not know that they have been infected for a long time and many of the patients who do learn about their infection are diagnosed in late stages of the disease. Approximately 38% of the people diagnosed with HIV infection progress to AIDS within a year of the first positive test results. The HIV transmission rate from a person aware of their infection is 3.3% in comparison to 11.4% of those who are unaware of the disease. It has also been proven that with a high quality care a 25-year-old HIV positive person can live additionally up to 39 years. HIV testing is very important to reduce the rate of new infections since people who are unaware of their disease are more likely to engage in risk behavior in comparison to the person who knows about their infection. (Renee Stein et al. 2011)

Counseling given to the patient post the test and result, is very critical because it is the opportunity to get the HIV-positive person a care that is needed. Thorough counseling and providing information at the time of diagnosis and clear standards of active referrals to care by the CTR staffs and more link to care activities might help increase the quality of the patient's life. (Renee Stein et al. 2011)

Both testing and counseling of HIV/AIDS are very crucial in prevention and care of the disease. By using counseling and giving information on HIV/AIDS uninfected individual can insure that they stay safe and avoid risking themselves, while a person who is infected can avoid transmission and get care and referrals to care. Counseling is also very important to avoid mother to child transmission and increase the access of HIV/AIDS care and Antiretroviral drug therapy as well. Offering HIV counseling and testing (HCT) in health care settings will increase availability of the care for the infected people. The regular HTC is provided by health care workers and it offers testing to all the patient irrespective of their presenting symptoms. (Rhoda. K. Wanyenza et al. 2008)

Counseling HIV/AIDS patient including an interview to help find out how that person got infected can also be helpful for the person to understand and accept the reality specially when the person has acute HIV infection. This help put some light on unique aspects of acute HIV infection diagnosis and counseling which will be understood and dealt with by the patient. Individual with acute HIV infection have more potentials of transmitting the disease to healthy individuals and hence increasing the growth of the epidemic so the counseling helps them understand risk behavior. For future intervention to reduce the transmission of the disease Acute HIV infection will need to find ways to transfer the information more saliently and possibly through more cultural and meaningful approaches. (Benjamin J. Wolpaw 2014)

## **5.2 Stigma of HIV/AIDS**

Many of the HIV/AIDS associated stigmas has been found as a barrier of HIV testing. Uptake of the testing services remains low and research in developing and developed countries has shown number of barriers and amongst them one is stigma. A social process through which individuals are devalued on the basis of particular negatively perceived characteristics or status can be defined as stigma, and because of these stigmas people fear to come forward for testing and counseling and seeking care. People fear of both internalized stigma and stigmatization serves as a barrier to HIV/AIDS. People who express shame, guilt, and social disapproval towards the people living with HIV/AIDS are less likely to test for HIV/AIDS. People who considered testing for the disease was in fear of stigmatization if tested positive is the key reason for not testing. (Sumaya Mall et al. 2012)

The categories of stigma that people suffered were:

Self-inflicted stigma: After being positively diagnosed with HIV, patient were left depressed and fearful of how others would treat them which caused many of them to withdraw from socializing even before the symptoms develop.

Family-inflicted stigma: Some patient described receiving inapt care and being left alone when they reveled having tested positive to HIV/AIDS. Relatives of the patient thought care and resources given to the patient was a waste since the disease is terminal.

Community-inflicted stigma: When the person with HIV/AIDS discloses that they have HIV/AIDS was treated with apprehension and discrimination. (Barbara Nyanzi-Wakholi et al 2009)

**Figure 3 : Demographic characteristic survey of HIV/AIDS inn survey**

p-value	2008 (survey 2) Total n=1281â n (%)	2004 (survey 1) Total n=640â n (%)	Demographic characteristics
0.07	27 years (IQR: 22-33)	27 years' (IQR:21-36)	Age: Medium (interquartile range IQR
0.04	552(44%) 715(56%)	251(41%) 354(59%)	Gender Male Female
<0.001	159(14%) 834(72%) 165(14%)	150(26%) 370(63%) 64(11%)	Education Primary Secondary Tertiary
<0.001	386(31%)	260(47%9	Employed Yes

	840(69%)	294(53%)	No
--	----------	----------	----

In the figure above shows the demographic sampling of the year 2004 and 2008, these samples were comparable on age and gender but the participants in 2008 were reportedly had higher level of education. The survey showed that more participants had more information on HIV/AIDS than in 2004 and that they had access to more knowledge through newspapers in health centers or hospitals. This compared to the access of the information provided in the school and from family remained to be the same in both years. There were additional questions about educational and research activities that were asked in 2008 survey through which it was found that 27% of the participants had acquired information regarding HIV/AIDS from conversations in the community or from research studies itself.

Small et al 2013 also state that in 2008 there were more people who reported of knowing someone with HIV/AIDS or a family member with HIV positive. The article also states that the stigma related to HIV/AIDS comparatively lowered in 2008 than in 2004. Also people going for voluntary HIV testing had increased in 2008. (Mall et al. 2013)

### **5.3 Experience and fears of the patient diagnosed with HIV/AIDS**

In an article surveyed by Barbara Nyanzi-wakaholi et al 2009, a participant in the survey described the experience of testing HIV positives as haunting feeling with only thoughts of the nearing death. One of the female describes finding out about being HIV positive as the thought of the pain HIV would bring in her life and the feeling of collapsing and desperate where all she could think about was that she was going to die and life was running out. They had fear that their life would have to go through significant amount of change and how the community that they were living in if they find out about the infection would look them upon.

Another female participant was worried about how her children would survive having fear of leaving these children in such a young age.

There was a fear of the people who tested positive about not being able to work and provide financial security for the family due to bad health conditions, which they blamed on the disease that was only progressive in nature. They were upset because they had no other option but to sell the land and other assets to support the people who were dependent on them.

People experienced that the repeated post-test counseling and sharing of the experiences with each other they were having and their belief in the religion that they had was helping them to overcome the fears.

The fear of other people knowing about them being infected was almost with all the participants, some of them would rather go to a herbalist at night and ask for herbal medicines which would be delivered to their homes than to go a health centers to receive Anti retroviral treatments (ART). The understanding of the ART was found to be less in lot of participants though there were some people who were opting for a different kind of cure, there were also few participants who were also participating in the ART and were satisfied with the outcomes, with one participant saying that they would be dead and buried by now if they would not have been in ART .

In another study by Benjamin J. Wolpaw et al 2014 performed in khayelitsha township of the western Cape of South Africa in public youth clinic, participants described the moment they had find out about the infection that they had a significant emotional response like being in shock, anger and depression along with the fear of dying and also one of the participant even said that he/she thought about committing suicide. Only few of the participants had reached the level of comfort compared to others who were still distressed by the test result.

#### 5.4 Barriers of HIV/AIDS counselling

CTR is one of the ways that a patient who has been recently diagnosed with HIV infection can get into much-needed medical and other additional support. Even when trying to get the help accessible for people infected yet the infected people come into care late. There have been several studies to find the link both in an individual and system level to get factors are acting as barriers in the late entry of the people infected into the care system. Pamela Morse Garland et al 2011.

According to the study carried out by the team, few of the barriers that could have played role in the delayed entry of the patient into the care system could be:

Dissatisfaction with the testing and counseling: Dissatisfaction had raised basically because of the lack of counseling or not enough amount of counseling or in some cases the quality of the counseling provided not being up to the mark. A participant in the survey said that because of the inadequate counseling given he/she had to seek for support outside socially with the family and friends who fortunately were there for counseling. And for some other, the person providing the counseling were not appropriately counseling them, making them feel like it was an end of the world and that the counselor had a very serious tone, which made the patient, feel bad. Experiences of the counselor not being considerate how a person diagnosed with the HIV would be feeling lead to people not wanting to ever go back to the care again.

System level barrier: The participant of the study frequently thought of the barriers in system level like criminal justice system, HIV care system or health insurance. Not having enough financial support or not having insurance was seen as the basic reason for patient to not taking part in HIV related care and follow-up services. When patient tried to get the state funded HIV care and Follow up services they found it be time consuming and difficult to access.

Some of the participant described that the barrier for them to get into a care system was that they did not get enough counseling during the diagnosis itself. They needed to be counseled more than what was done to help them make understand the disease and the care that they could get.

Depending on what experiences the participant had shared it could be said that the counseling and follow up services were done just once with them which clearly was not enough.

Individual level barrier: Many participants expressed that they themselves were a barrier towards the progress towards the HIV care entry. Most of the barrier were being identified as HIV positive person in the community, wanting to have privacy, having no trust towards the medical provider, lack of motivation in themselves, feeling of shame and having co-morbidities. One of the participant even described herself of being own's worst enemy (Pamela M Garland et al 2011)

HIV/AIDS related stigma: In another study, HIV related stigma could be directly related to the use of VCT (Voluntary HIV counseling and treatment) in the areas like Ethiopia, Humara and other SSA countries. Stigma that the people were facing was blemishes on the individual's character like behavior that were not accepted by the community e.g. sexual behavior, involvement in or with sex workers, drug uses, migrant workers and the poor, anathema or curse of body and tribal identity.

Some examples like relatives not wanting to provide care for the person infected with HIV/AIDS, not wanting to buy things from the infected person's shop or not willing to provide employment to infected person are some instrumental stigma of HIV/AIDS which comes as a barrier in people wanting to identify themselves as infected and seek care and follow-up programs. (Tesfaye H Leta et al 2012)

## **5.5 Community based interventions and voluntary counseling**

Community based intervention have been seen to have helped prevent and control HIV infection by increasing knowledge of the people hence changing the risk taking behaviour and practises. (Rehana. A Salam et al 2012)

HIV can be prevented idealistically only by voluntary participation of the infected person and the accessibility of the services to these people when they have

enough knowledge and proper information about the disease and get strong support from the health care system. (Rehana A Salam et al 2012).

The same study has pointed out that the amount of safe sex had increased by 19% by just community based interventions like a street outreach activities.

Intervention programs has resulted in decreased HIV infections in the clinical trials and also shown encouragement in early HIV treatment and ART to prevent a child getting infected through the mother. CBIs compared to the standard voluntary counseling could improve the community norms about getting tested and reduce stigma of HIV/AIDS, help them get the support both medical and emotional and decrease the infection. (Thomas J Coates. Et. Al 2014)

Study carried by W. Kipp et al 2002 in rural part of Uganda states that HIV CT was high in demand and the demand had to met keeping in mind of what kind of counseling and intervention was needed for the local population of an area also keeping a balanced professional judgement and cost effective services even though in the past the HIV counseling and treatment has not given any significant result in the HIV incidence.



## 6 Discussion

### 6.1 Ethics and Reliability

A qualitative research allows researcher to get at the inner experience of the participants, to determine how meanings are formed through and in culture and to discover rather than test variables. (Corbin, Strauss 2008)

Qualitative research is an umbrella term for an array of attitudes towards and strategies for conducting inquiry that are aimed at the discovering how human beings understand, experience, interpret, and produce the social world.(Hammerslay 2012).

It is reasonable to assume that everyone carries a set of morals, which manifest themselves in a person's behaviour, especially towards other people. The person does not need to be aware of his or her moral positions and does not need to reflect on them. The specific values and positions these morals can be assumed to consist of need also not be particularly consistent with each other. They do not need to exhibit any systematics whatsoever, and the person does not need to be able justify him or herself in any way. Through choices and actions, a person shows what his or her morals are. (Hermeren 2011).

Scientific articles as a basic reference while writing this thesis so it holds its ethical values and is reliable. Articles published from 2000 to 2014 so latest information that is available could be collected. All the data that has been given in the thesis are being taken from scientific research done around the world by very qualified intellectual people and so the reliable.

## 6.2 Analysing the results

The aim of my thesis was to get information on HIV/AIDS and the counseling and treatment regarding the disease. I wanted to know how a person who has been recently diagnosed with this disease handles their life and what kind of services medically and emotionally are available for them in the places that are mostly affected from this disease. I wanted to see if the counseling has helped bring some change in the risk behavior and helped preventing the disease from spreading. I also wanted to know about the stigma that came with the disease that is known as one of the barriers for the prevention and control of the disease. I could find articles in these subjects but I could not find information on the role of the nurses in counseling and treatment in the system regarding HIV/AIDS. It was really difficult to find information on how and what a nurse could do and what problem they could face with the population while working professionally.

Though it was found that counseling did act as a support for the person diagnosed with HIV/AIDS yet just one time counseling was not enough for most of the patient. Also the lack of information about HIV/AIDS stood as a major barrier to control the disease and that people had extreme amount of fear after being diagnosed because of the stigma that came into play in their community making their life difficult in so many levels.

It is very important that the patient discloses having tested positive to HIV for them to have proper treatment and prevent the disease from spreading. In many cases patient's belief about the treatment is more important than the actual treatment itself for them to disclose their status and the behavioral change after Anti retroviral treatment. (S.Skogmar et al 2006).

According to study done by Leon et al (2014) the closer involvement of the nurses with the process of HIV testing within the clinical STI consultation may have allowed nurses to more easily inform the patient of the medical benefits of seeking immediate referral for ART initiation.

In conclusion community based interventions and voluntary counseling done to the patient have been found to be more effective and the availability of the testing and

counseling of the patient stands as a hurdle for the prevention and care of the HIV/AIDS.

### **6.3 Further studies**

This Bachelor thesis could be further used in getting information on the barriers and the stigma that the person tested positive with HIV infection and the support that community based intervention can bring in their life's as well as knowing what has worked so far in controlling and preventing the disease which has spread world wide already. After getting the result I could see a lot of room for improvement as far as counseling is concern. There should be system level revise of what kind of support are needed and how a professionals can be given a job to get maximum benefit in prevention of the disease.

Finding articles, which was a research for the counseling of HIV/AIDS patient, was a challenge. There were very few articles that had directly researched the counseling and the barriers of counseling. So I think in future if research could be done in the ways of counseling and what barriers the nurses or the primary health worker were facing while counseling could be done specially from nurses aspects.

There were quite a lot of articles that had patient's prospective on how counseling was done but I think if there could be few research where nurses or health professional share their prospective of how they are handling the counseling and if they think they have been themselves been provided with necessary equipment, information to give counseling to a patient can be done.

### **6.4 Use of the thesis paper**

This thesis could be used in future by the nursing students to know about the core reasons the prevention of the disease has been a challenge. The students can find the barriers and can further research more theories on how and why are there so less amount of community based interventions are done up until now and that how

can many stigmas be tackled with. It can also be used by the other health professionals to know about the experiences and the fears of the patient and why they fail to report the new cases if the HIV/AIDS immediately and not at the last stage.

## BIBLIOGRAPHY

Anssi Peräkylä 2005. Patient's response to interpretations. A dialogue between conversation analysis and psychoanalytic theory. [163-173]

Anssi Peräkylä 2003. Conversation analysis and the professional stocks of interactional knowledge. [727-749]

Barbara Nyanzi-Wakholi, Antonieta Medina Lara, Christine Watera, Paula Munderi, Charles Gilks, Heiner Grosskurth. 2009. The role of HIV testing, counseling, and treatment in coping with HIV/AIDS in Uganda: a qualitative analysis. [903-905].

Benjamin J. Wolpaw, Catherine Mathews, Yolisa Mtshizana, Mickey Chopra, Diana Hardie, Mark N Lurie, Virginia De Azevedo, Karen Jennings. 2014. Patient experiences following HIV infection diagnosis and counseling in South Africa. [1-2]

British Association for counseling and psychotherapy 1986. <http://www.bacp.co.uk/>

Carole Torgerström. 2003. Systematic review. [15]

Eugene Tsang. Guide to patient counseling. 2008. <http://www.cuhk.edu.hk/>

John Mcleod & Julia Mcleod. 2007. Counseling skills: A practical guide for counsellor and helping professionals. [25-26]

K. E Nye, J. M. Parkin .HIV and AIDS 1994.[2-6]

Kimberley A. Nevedrof. The content analysis guidebook 2002 [1]

L. Waters, D. Asboe. ABC and HIV/AIDS 6<sup>th</sup> edition 2012 [25]

Michael W. Adler 2001. ABC of AIDS [1-3]

Natalie Leon, Catherine Matthews, Simon Lewin, Meg Osler, Andrew Boules, Carl Lombard. 2014. A comparison of linkage to HIV care provider-initiated HIV testing and counseling (PITC) versus voluntary HIV counseling and testing (VCT) for patients with sexually transmitted infections in Cape Town, South Africa. [10]

Paul. E. Sax, Calvin j. Cohen. HIV essentials 6<sup>th</sup> edition 2013 [4-5]

Pippa Hemingway, Nic Brereton 2009. What is systematic review? [2-4].

Pamela M Garland, Eduardo.E Valverde, Jennifer Fagan, Linda Beer, Catherine Sanders, Daniel Hillman, Kathleen Brady, Maria Courogen, Jeanne Bertolli. 2011. HIV counseling, testing and referral experiences of person diagnosed with HIV who have never entered HIV medical care. [117-125].

Philip Mayring. 2014. Qualitative Content Analysis Theoretical Foundation, Basic Procedure and Software Solution.[39]

Pirjo kaakinen, Maria kääriäinen, Helvi kyngäs. 2012. Journals of nursing education and practice.

Renee Stein, Tanisha S. grimes, Robert Malow, Dale Stratford, Freya Spielberg, David R. Holtgrave .2011. Introduction to special supplement. Monitoring and evaluation of HIV counseling, testing and referral (CTR) and HIV testing services. [1-5].

Rehana A Salam, Sarah Haroon, Zulfiqar Bhutta. 2012. Impact of community based interventions on HIV knowledge, attitude, and transmission. [1]

Rhoda K Wanyenza, Cecilia Nawavvu, Alice S Namle, Bernard Mayanja, Rebecca Bunnell, Betty Abang, Gideon Amanyire, nelson K Sewankambo, Moses R Kamya. 2008. Acceptability of routine HIV counseling and testing, and HIV seroprevalence in Ugandan hospitals. [302]

Rosemary A. Thompson 2003. Counseling techniques, Improving relationship with others, our families, our environment and us.

Seagon 1992 HIV and AIDS. [13,621]

S. Kartikeyan, R.N Bharmal, R.P Tiwari, P.S Bisen. HIV and AIDS basic elements and priorities 2007. [48-49]

Steve Stemler 2001. An overview of content analysis. Practical assessment research and evaluation [7,17] <http://pareonline.net/getvn.asp?v=7&n=17>

Sumaya Mall, Keren Middelkoop, Daniella Mark, Robin wood, Linda-Gail Bekker.2011. Changing patterns in HIV/AIDS syigma and uptake of voluntary counseling and testing services: The result of two consecutive surveys conducted in Western Cape, South Africa. [194-198].

S. Skogmar, D. Shakely, M. Lans, J. Danell, R. Andersson, N. Tshandu, A. Oden, S. Roberts, W. D. Francois Venter. 2006. Effects of antiretroviral and counseling on disclosure of HIV-serostatus in Johannesburg, South Africa. [730].

Tesfaye H Leta, Ingvild F Sandøy, Knut Fylkesnes. 2012. Factors affecting voluntary counseling and testing among men in Ethipia: a cross-sectional survey. [1,5,7-9].

Thomas J. Coates, Michal Kulich, David D Celentano, Carla E Zelaya, Suwat Chariyalertsak, Alfred Chingano, Glenda Gray, Jessie K K Mbwambo, Stefen F Morin, Linda Richter, Michael Sweat, Heidi Van Rooyen, Nuala McGrath, Agnés Fiamma, Oliver Laeyendecker, Estelle Piwowar-Manning, Greg Szekeres, eborah Donnell, Susan H Eshleman, the NIMH project accept (HPTN 043) study team.2014. Effect of community based voluntary counseling on HIV incidence and social and behavioural outcomes: a cluster-randomized trial. [267].

UNAIDs tech update 1997 Counseling and HIV/AIDS

[http://data.unaids.org/publications/irc-pub03/counstu\\_en.pdf](http://data.unaids.org/publications/irc-pub03/counstu_en.pdf)

W. Kipp, G. Kabagambe, J. Konde-lule.2002. HIV counseling and testing in rural Uganda: Communities' attitude and perception towards an HIV counselingand testing. [699,705].





**APPENDIX 1. Process of searching for information**

DATABASE	KEYWORDS	HITS	USED
Chinahl	HIV/AIDS and counseling  Barriers of counseling in HIV/AIDS	924	8
Pubmed	Counseling HIV/AIDS patient  Counseling in HIV/AIDS.	1210	4